'Recovery and the Conspiracy of Hope'
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     ...I want to share with you what it is like to be diagnosed at a young
age with mental illness and to lose all hope.  I want to tell you about the
dark winter of anguish and apathy when we give up hope and just sit and smoke
and drink coffee.

     For those of us who have been diagnosed with mental illness and who have
lived in the sometimes desolate wastelands of mental health programs and
institutions, hope is not just a nice sounding euphemism.  It is a matter of
life and death.  We know this because, like the sea rose, we have known a
very cold winter in which all hope seemed to be crushed out of us. It started
for most of us in the prime of our youth.  At first we could not name it.  It
came like a thief in the night and robbed us of our youth, our dreams, our
aspirations and our futures.  It came upon us like a terrifying nightmare
that we could not awaken from.

     And then, at a time when we most needed to be near the one's we loved, we
were taken away to far off places.  At the age of 14 or 17 or 22 we were told
that we had a disease that had no cure.  We were told to take medications
that made us slur and shake, that robbed our youthful bodies of energy and
made us walk stiff like zombies.  We were told  that if we stayed on these
medications for the rest of our lives we could perhaps maintain some
semblance of a life. They kept telling us that these medications were good
for us and yet we could feel the high dose neuroleptics transforming us into
empty vessels. We felt like will-less souls or the walking dead as the
numbing indifference and drug induced apathy took hold.  At such high
dosages, neuroleptics radically diminished our personhood and sense of self.

     As these first winds of winter settled upon us we pulled the blankets up
tight around our bodies but we did not sleep.  During those first few nights
in the hospital we lay awake.  You see, at night the lights from the houses
in the community shine through the windows of the mental institution. Life
still went on out there while ours crumbled all about us.  Those lights
seemed very, very far away. ...And indeed, this is how far away it felt in
the mental hospital. The road back home was not clear.  And as we lay there
in the darkness we were scared and could not even imagine the way out of this
awful place.  And when no one was looking we wept in all of that loneliness.

     But when morning came we raged.  We raged against the bleak prophesies
that were being made for our lives. They are wrong!  They are wrong!  We are
not crazy.  We are not like those other ones over there who have been in this
hospital too long.  We are different.  We will return home and everything
will be just the same.  It's just a bad dream.  A temporary setback.

     In time we did leave the hospital.  We stood on the steps with our
suitcases in hand.  We had such courage – our youthful optimism waved like
triumphant flags at a homecoming parade.   We were going to make it.  We were
never going to come back to the hospital again.

Some did make it.  But most of us returned home and found that nothing was the same anymore.  Our friends were frightened of us or were strangely absent.  They were overly careful when near us.  Our families were distraught and torn by guilt.  They had not slept and their eyes were still swollen from the tears they cried.  And we, we were exhausted.  But we were willing to try.  And I swear, with all the courage we could muster we tried to return to work and to school, we tried to pick up the pieces, and we prayed for the strength and perseverance to keep trying.  But it seemed that God turned a deaf ear to our prayers.  The terrible distress came back and our lives were shattered once again.

And now our winter deepened into a bone chilling cold.  Something began to die in us. Something way down deep began to break. Slowly the messages of hopelessness and stigma which so permeated the places we received treatment, began to sink in.  We slowly began to believe what was being said about us. It seemed that the system tried to break our spirit and was more intent on gaining, even coercing our compliance, than listening to us and our needs.

We found ourselves undergoing that dehumanizing transformation from being a person to being an illness: "a schizophrenic", "a multiple", "a bi-polar" (Deegan 1992).  Our personhood and sense of self continued to atrophy as we were coached by professionals to learn to say, "I am a schizophrenic"; "I am a bi-polar"; "I am a multiple". And each time we repeated this dehumanizing litany our sense of being a person was diminished as "the disease" loomed as an all powerful "It", a wholly Other entity, an "in-itself" that we were taught we were powerless over.

 Professionals said we were making progress because we learned to equate our very selves with our illness.  They said it was progress because we learned to say "I am a schizophrenic". But we felt no progress in this.  We felt time was standing still.  The self we had been seemed to fade farther and farther away, like a dream that belonged to somebody else. The future seemed bleak and empty and promised nothing but more suffering.  And the present became an endless succession of moments marked by the next cigarette and the next.

So much of what we were suffering from was overlooked. The context of our lives were largely ignored. The professionals who worked with us had studied the science of physical objects, not human science.  They did not understand what the neurologist Oliver Sacks (1970) so clearly articulates: "To restore the human subject at the center – the suffering, afflicted, fighting, human subject – we must deepen a case history to a narrative or tale; only then do we  have a 'who' as well as a 'what', a real person, a patient, in relations to disease – in relations to the physical. . . the study of disease and identity cannot be disjoined. . . (stories) bring us to the very intersection of mechanism and life, to the relation of physiological processes to biography" (p.viii).  But no one asked for our stories. Instead they thought our biographies as schizophrenics had been already been written nearly a century before by Kraeplin and Blueler.

 Yet much of what we were going through were simply human experiences – experiences such as loss and grief and shock and fear and loneliness.  One by one our friends, relatives and perhaps even families left us.  One by one the

professionals in our lives moved on and it became too difficult to trust anyone.  One by one our dreams and hopes were crushed.  We seemed to lose everything.  We felt abandoned in our ever-deepening winter.

     The weeks, the months or the years began to pass us by.  Now our aging was no longer marked by the milestones of a year's accomplishments but rather by the numbing pain of successive failures.  We tried and failed and tried and failed until it hurt too much to try anymore.  Now when we left the hospital it was not a question of would we come back, but simply a question of when would we return.  In a last, desperate attempt to protect ourselves we gave up.  We gave up trying to get well.  Giving up was a solution for us.  It numbed the pain. We were willing to sacrifice enormous parts of ourselves in order to say "I don't care". Our personhood continued to atrophy through this adaptive strategy of not caring anymore.  And so we sat in chairs and smoked and drank coffee and smoked some more.. It was a high price to pay for survival.  We just gave up. And winter settled in upon us like a long cold anguish.

     I'm sure that many of us here today know people with psychiatric disabilities who are lost in the winter of anguish and apathy I have just described.  It is a time of real darkness and despair.  Just like the sea rose in January and February, it is a time when nothing seems to be growing except the darkness itself.  It is a time of giving up.  Giving up is a solution.  Giving up numbs the pain because we stop asking "why and how will I go on?".  Even the simplest of tasks is overwhelming at this time.  One learns to be helpless because that is safer than being completely hopeless.

     The winter of anguish and the atrophy of the sense of self that I am describing is a hell not only for the ones living it, but also for the one's who love and care for us: friends, relatives and even professionals.  I have described what it feels like on the inside as it is being lived.  But friends, relatives and professionals see the anguish and indifference from the outside.

   From the outside it appears that the person just isn't trying anymore.  Very frequently people who show up at clubhouses and other rehabilitation programs are partially or totally immersed in this despair and anguish. On good days we may show up at program sites but that's about all.  We sit on the couch and smoke and drink coffee.  A lot of times we don't bother showing up at programs at all.  From the outside we may appear to be among the living dead.  We appear to be apathetic, listless, lifeless.  As professionals, friends and relatives we may think that these people are "full of excuses", they don't seem to try anymore, they appear to be consistently inconsistent, and it appears that the only thing they are motivated toward is apathy.  At times these people seem to fly into wishful fantasies about magically turning their lives around.  But these seem to us to be only fantasies, a momentary refuge from chronic boredom. When the fantasy collapses like a worn balloon, nothing has changed because no real action has been taken.  Apathy returns and the cycle of anguish continues.

     Staff, family and friends have very strong reactions to the person lost in the winter of anguish and apathy. From the outside it can be difficult to truly believe that there really is a person over there. Faced with a person who truly seems not to care we may be prompted to ask the question that

Oliver Sacks (1970, p. 113) raises: "Do you think William (he) has a soul? Or has he been pithed, scooped-out, de-souled, by disease?" I put this question to each of us here today. Can the person inside become a disease? Can schizophrenia pith or scoop-out the person so that nothing is left but the disease?  Each of us must meet the challenge of answering this question for ourselves. In answering this question, the stakes are very high.  Our own personhood, our own humanity is on the line in answering this question.  Let me explain:

    Sitting in the day room, literally couched in a cigarette smoke screen, the profound apathy and indifference we may encounter in another person will challenge our own humanity and our own capacity to be compassionate. We may question whether there really is a person over there.....

    However, when faced with a person lost in anguish and apathy, there are a number of  more common responses than finding a way to establish an I-Thou relationship. A frequent response is what I call the "frenzied savior response". We have all felt like this at one time or another in our work. The frenzied savior response goes like this : The more listless and apathetic the person gets, the more frenetically active we become.  The more they withdraw, the more we intrude.  The more will-less they become, the more willful we become.  The more they give up, the harder we try.  The more despairing they become, the more we indulge in shallow optimism.  The more treatment plans they abort, the more plans we make for them. Needless to say we soon find ourselves burnt out and exhausted.  Then our anger sets in.

    Our anger sets in when our best and finest expectations have been thoroughly thwarted by the person lost in anguish and apathy.  We feel used and thoroughly unhelpful.  We are angry. Our identities as helping people are truly put to the test by people lost in the winter of anguish and indifference. At this time it is not uncommon for most of us to begin to blame the person with the psychiatric disability at this point.  We say things like : "They are lazy.  They are hopeless. They are not sick, they are just manipulating.  They are chronic. They need to suffer the natural consequences of their actions. They like living this way. They are not mad, they are bad.  The problem is not with the help we are offering, the problem is that they can't be helped.  They don't want help.  They should be thrown out of this program so they can 'hit bottom'.  Then they will finally wake up and accept the good help we have been offering."

    During this period of anger and blaming a most interesting thing happens.  We begin to behave just like the person we have been trying so hard to save.  Frequently at this point staff simply give up.  We enter into our own despair and anguish. Our own personhood begins to atrophy.  We too give up.  We stop trying.  It hurts too much to keep trying to help the person who seems to not want help.  It hurts too much to keep trying to help and failing.  It hurts too much to keep caring about them when they can't even seem to care about themselves.  At this point we collapse into our own winter of anguish and a coldness settles into our hearts.

    We are no better at living in despair than are people with psychiatric disabilities.  We cannot tolerate it so we give up too.  Some of us give up by simply quitting our jobs.  We reason that high tech computers do as they are told and, besides, the pay is better.  Others of us decide not to quit,

but rather we grow callous and hard of heart.  We approach our jobs like the man in the Dunkin Donuts commercial: "It's time to make the donuts, it's time to make the donuts".  Still others of us become chronically cynical.  We float along at work like pieces of dead wood floating on the sea, watching administrators come and go like the weather; taking secret delight in watching on more mental health initiative go down the tubes; and doing nothing to help change the sytem in a constructive way.  These are all ways of giving up.  In all these ways we live out our own despair.

Additionally entire programs, service delivery systems and treatment models can get caught up in this despair and anguish as well.  These systems begin to behave just like the person with a psychiatric disability who has given up hope.  A system that has given up hope spends more time screening out program participants than inviting them in.  Entry criteria become rigid and inflexible.  If you read between the lines of the entry criteria to such programs they basically state: If you are having problems come back when they are fixed and we will be glad to help you. Service systems that have given up hope attempt to cope with despair and hopelessness by distancing and isolating the very people they are supposed to be serving. Just listen to the language we use: In such mental health systems we have "gatekeepers" whose job it is to "screen" and "divert" service users.  In fact, we actually use the language of war in our work.  For instance we talk about sending "front-line staff" into the "field" to develop treatment "strategies" for "target populations".

Is there another alternative?  Must we respond to the anguish and apathy of people with psychiatric disability with our own anguish and apathy?  I think there is an alternative.  The alternative to despair is hope. The alternative to apathy is care. Creating hope filled, care filled environments that nurture and invite growth and recovery is the alternative.

Remember the sea rose?  During the cold of winter when all the world was frozen and there was no sign of spring, that seed just waited in the darkness.  It just waited.  It waited for the soil to thaw. It waited for the rains to come.  When the earth was splintered with ice, that sea rose could not begin to grow. The environment around the sea rose had to change before that new life could emerge and come into being.

People with psychiatric disabilities are waiting just like that sea rose waited.  We are waiting for our environments to change so that the person within us can emerge and grow.

Those of us who have given up are not to be abandoned as "hopeless cases".  The truth is that at some point every single person who has been diagnosed with a mental illness passes through this time of anguish and apathy, even if only for a short while.  Remember that giving up is a solution. Giving up is a way of surviving in environments which are desolate, oppressive places and which fail to nurture and support us.  The task that faces us is to move from just surviving, to recovering.  But in order to do this, the environments in which we are spending our time must change.  I use the word environment to include, not just the physical environment, but also the human interactive environment that we call relationship.

From this perspective, rather than seeing us as unmotivated, apathetic,

or hopeless cases, we can be understood as people who are waiting.  We never know for sure but perhaps, just perhaps, there is a new life within a person just waiting to take root if a secure and nurturing soil is provided.  This is the alternative to despair.  This is the hopeful stance.  Marie Balter expressed this hope when asked, "Do you think that everybody can get better?" she responded: "It's not up to us to decide if they can or can't.  Just give everybody the chance to get better and then let them go at their own pace. And we have to be positive - supporting their
desire to live better and not always insisting on their productivity as a measure of their success". (Balter 1987, p.153).

Source:  http://www.bu.edu/resilience/examples/recovery-conspiracyofhope.txt

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